

## A Preliminary Study of the Development, Validity, and Reliability of A Caregiver Questionnaire for the Health-related Quality of Life in Children with Cerebral Palsy

Wen-Yu Liu, PT, PhD; Yu-Jen Hou<sup>1</sup>, PT, MS; Hua-Fang Liao<sup>3</sup>, PT, MS;  
Yang-Hua Lin, PT, PhD; Yu-Ying Chen<sup>4</sup>, PT, MS; Alice MK Wong<sup>2</sup>, MD

**Background:** In Taiwan, there is no disease-specific instrument to measure the health-related quality of life (HRQL) in children with cerebral palsy (CP). The goal of this preliminary study was to develop and test the validity and reliability of a caregiver questionnaire for HRQL in children with CP (CQ-HRQL-CP).

**Methods:** The CQ-HRQL-CP included 4 dimensions, motor ability, pain and emotion, interaction and participation, and satisfaction and expectation. The questions were modified based on the content validity index (CVI). A purposive sampling of 45 parents of children with CP completed tests of the item discriminant validity and internal consistency. Twenty of these parents were randomly recruited for further testing of the test-retest reliability.

**Results:** The CVI of individual items and dimensions was 0.86~1. With regard to the item discriminant validity, items which correlated more strongly with other dimensions than with their own dimensions were deleted. The adjusted Cronbach's coefficient value was 0.87~0.99. The test-retest reliability, evaluated using an intraclass correlation coefficient (ICC<sub>(3,1)</sub>), was 0.86~0.99 for each dimension.

**Conclusions:** The content validity, item discriminant validity, internal consistency, and test-retest reliability of this new CQ-HRQL-CP were acceptable. Further study of the concurrent validity of the CQ-HRQL-CP is needed.

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**Key words:** cerebral palsy, health-related quality of life, validity, reliability

Cerebral palsy (CP) is a common cause of restricted mobility in daily activities among children.<sup>(1)</sup> The International Workshop on the Definition and Classification of CP describes the condition as “a group of developmental disorders of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred

in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder”.<sup>(2)</sup> This new definition emphasizes the fact that CP frequently causes various manifestations and has a multidimensional impact. Therefore, when

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From the Department of Physical Therapy, College of Medicine, Chang Gung University, Taoyuan, Taiwan. <sup>1</sup>Department of Physical Medicine and Rehabilitation, Chang Gung Memorial Hospital at Chiayi, Chang Gung University College of Medicine, Taoyuan, Taiwan; <sup>2</sup>Department of Physical Medicine and Rehabilitation, Chang Gung Memorial Hospital at Taoyuan, Chang Gung University College of Medicine, Taoyuan, Taiwan; <sup>3</sup>Department of Orthopedic Surgery, Chang Gung Children's Hospital at Linkou, Taoyuan, Taiwan; <sup>4</sup>School of Graduate Institute of Physical Therapy, College of Medicine, National Taiwan University, Taipei, Taiwan.

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Correspondence to: Dr. Alice MK Wong, Department of Physical Medicine and Rehabilitation, Chang Gung Memorial Hospital at Taoyuan. 123, Dinghu Rd., Jiulu Village, Gueishan Township, Taoyuan County 333, Taiwan (R.O.C.)

Tel.: 886-3-3281200 ext. 2655; Fax: 886-3-3198222; E-mail: walice@cgmh.org.tw

determining the outcomes of children with CP, health professionals and educators should take the overall condition into account from different perspectives rather than focus on the specific developmental domain. Health-related quality of life (HRQL) has recently been deemed to represent the total effect of individual and environmental factors on daily function and health status.<sup>(3)</sup> Therefore, the examination of HRQL is very important in children with CP.

HRQL, exclusive of the influence of politics and the economy as well as religion, can be defined from the viewpoint of an individual who has been undergoing both functional changes through an accident / treatment and the impairments of physical, psychological and social components due to the disorder.<sup>(3-6)</sup> Schipper et al. also outlined 4 domains of HRQL; (1) physical and occupational function, (2) psychological function, (3) social interaction, and (4) somatic sensation.<sup>(7)</sup> Clinicians adopt HRQL in patients to measure the effects of chronic illnesses to gain a comprehensive understanding of how an illness interferes with an individual's day-to-day life from a broad perspective.<sup>(4-6)</sup> In addition, HRQL can be used as an important outcome measure to determine the effectiveness of rehabilitation and educational services in children with CP.

Specifically speaking, HRQL is categorized into generic and disease-specific measures. To be applicable in a large population,<sup>(8)</sup> generic HRQL measures featuring a wide variety of usage are designed to discriminate groups which have proved unresponsive to the specific effects of a disease process clinically.<sup>(4,8,9)</sup> In contrast, disease-specific measures, characterized as better indicators of treatment effects, are sensitive to small changes in the domain of concerns for a particular population and cannot help but find themselves difficult to make HRQL compared across populations under circumstances subject to their innate specificity.<sup>(8)</sup>

There are a growing number of papers on the assessment of HRQL in children with CP, with measures which have been developed to some extent for children with CP.<sup>(10)</sup> Common generic HRQL measures include of the Child Health Questionnaire (CHQ) and the generic core scales of the Pediatric Quality of Life instrument (PedsQL),<sup>(11,12)</sup> while disease-specific measures are illustrated by the Caregiver Questionnaire.<sup>(13)</sup> But for quite a few limitations drawn from clinical trials, the existing mea-

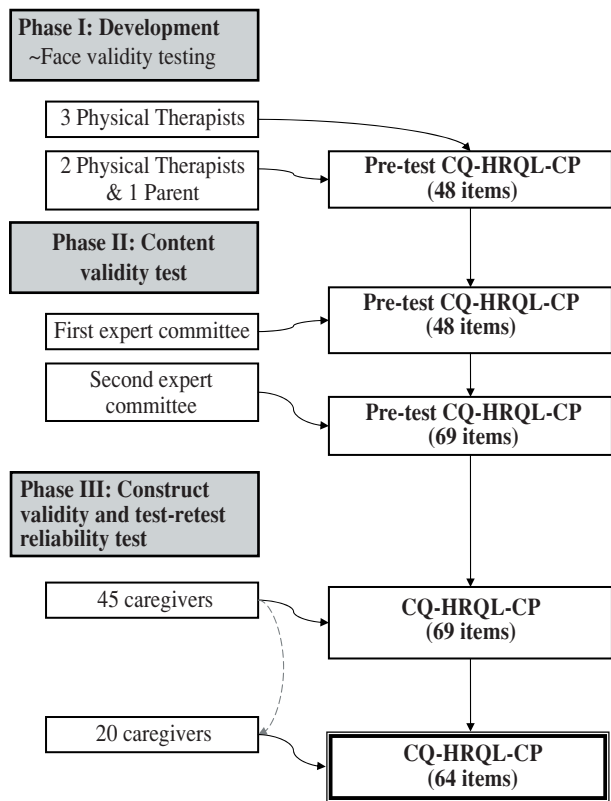
asures in HRQL would be considered sound and satisfactory,<sup>(14)</sup> and the awareness that there have been no validated HRQL measures available in Taiwan.<sup>(15)</sup> Furthermore, using validated pediatric HRQL instruments which were originally developed and validated in the U.S.A. and Europe is not only costly but also causes ambiguity in terms of syntactic differences between western languages and native ones spoken in Taiwan. Cultural variations also cause concern.<sup>(16)</sup> The goal of this study was to develop and test the validity and reliability of a new caregiver questionnaire for HRQL in children with CP (CQ-HRQL-CP), which was developed specifically to assess HRQL in 4- to 14-year-old children with CP.

## METHODS

The institutional review board of Chang Gung Memorial Hospital approved participation in the data collection process. The study consisted of 3 phases (Fig. 1). In the first phase, a 48-item questionnaire was developed by 3 physical therapists. The face validity was checked by 2 other physical therapists and a parent of a child with CP. In the second phase, the first draft of the CQ-HRQL-CP was revised and validated by 2 expert committees. The content validity and clinical use of the CQ-HRQL-CP were evaluated. In the third phase, testing of the discriminant validity, internal consistency, and test-retest reliability of the CQ-HRQL-CP was completed by 45 parents of children with CP. The 3 phases are described in detail below.

### Development and face validity of the preliminary CQ-HRQL-CP

An initial pool of 48 items was developed by 3 physical therapists based on a review of the literature on HRQL of 4- to 14-year-old children with CP. The most common format for obtaining the HRQL of children with CP is a proxy response by the parents. Furthermore, some children with CP are mentally handicapped and have motor involvement. Therefore, we designed a questionnaire for the caregivers (proxy response) to rate the child's typical daily HRQL on a 5-point Likert scale. A total of 48 items with 4 dimensions were examined, including motor ability (12 items), pain and emotion (4 items), interaction and participation (8 items), and satisfaction and expectation (24 items). Responses on the 5-



**Fig. 1** Flow chart of the development of the caregiver questionnaire on health-related quality of life in children with cerebral palsy (CQ-HRQL-CP).

point Likert scale were as follows: the “motor ability” dimension ranged from 0 (“unable to do”) to 4 (“able to do without any difficulty”), the “pain and emotion” dimension ranged from 0 (“always feel pain”) to 4 (“no pain or symptoms felt”), the “interaction and participation” dimension ranged from 0 (“never attend or participate in”) to 4 (“always attend or participate in”), and the “satisfaction and expectation” dimension ranged from 0 (“very dissatisfied/strongly disagree”) to 4 (“very satisfied/strongly agree”). Higher scores indicated a more favorable HRQL.

Two other physical therapists and a parent of a child with CP completed this 48-item CQ-HRQL-CP before the preliminary CQ-HRQL-CP was subjected to further psychometric testing. To simplify the text to make it as comprehensible as possible and to

ensure the goals of the current study and authors’ intentions remained intact, some modifications were flexibly implemented over the preliminary CQ-HRQL-CP.

### Content validity testing of the pre-test CQ-HRQL-CP

Two expert committees were invited to test the content validity of the CQ-HRQL-CP. This was done to obtain a subjective judgment on the degree of relevant construct in the questionnaire.<sup>(17)</sup> The custom-made checklist was designed in part to determine (A) the relevance of the items, (B) item clarity and conciseness, and (C) omissions of important aspects of HRQL in children with CP. Parts (A) and (B) comprised closed questions with 3-point Likert scales for ranking, and part (C) consisted of open questions to record the comments of the first expert committee. The content validity index (CVI) for each item and each dimension was determined by calculating the proportion of items that received a rating of at least 3 by the experts.

The 48-item CQ-HRQL-CP was reviewed by the first expert committee which included a pediatrician, a pediatric orthopedic surgeon, and 2 senior pediatric physical therapists with post-professional (beyond entry-level) master degrees in pediatric physical therapy. According to Waltz and Bausell, the CVI of a measure evaluated by 4 experts must be at least 0.75 to be considered acceptable.<sup>(18)</sup> None of the items in our questionnaire was deleted as the CVI scores of all items were > 0.75. The CVI of individual items and dimensions in the 48-item CQ-HRQL-CP ranged from 0.83 to 1, indicating an acceptable level of content validity. Based on the comments of the experts, some minor changes in the wording were made in 15 items, and 21 items were added.

The 69-item CQ-HRQL-CP was reviewed by the second expert committee which included a pediatrician, a pediatric orthopedic surgeon, 3 senior pediatric physical therapists with advanced degrees related to pediatric rehabilitation medicine, and 3 physical therapy faculty members with previous experience in establishing or using questionnaires for measuring HRQL in other populations with disabilities. According to Waltz and Bausell, the CVI of a measure evaluated by 7 experts must be at least 0.71 to be considered acceptable.<sup>(18)</sup> The CVI of individual items and dimensions in the 69-item CQ-HRQL-CP

ranged from 0.86 to 1, indicating an acceptable level of content validity. After evaluating the CVI scores, none of the items was deleted because all had CVI scores > 0.71. In addition, some minor changes in the wording were made in 27 items based on comments on their clarity and ease of use. As a result, the pre-testing CQ-HRQL-CP contained 69 items. The break-up of items for the 4 dimensions was as follows: (1) motor ability, 26 items; (2) pain and emotion, 7 items; (3) interaction and participation, 9 items; and (4) satisfaction and expectation, 27 items. The calculated scores were presented as percentages for each dimension.

### Psychometric testing of the CQ-HRQL-CP

Testing of Item Discriminant Validity, Internal Consistency, and Test-retest Reliability

#### Participants

A convenience sample of 45 caregivers of children with CP as enrolled from either the Children's Hospital or the Taoyuan Branch of Chang Gung Memorial Hospital, Taiwan, (R.O.C.). The inclusion criteria for the participants in the study were as follows: (1) they were caregivers of children with CP, (2) their children were between 4 and 14 years old, (3) their highest level of education was at least elementary school, and (4) they were literate, had no difficulty understanding simple written Chinese (Mandarin dialect) sentences and could demonstrate cognitive ability independently to complete the questionnaire. The exclusion criteria in the study were as follows: (1) their children had undergone a surgical procedure within the previous 3 months and (2) the Mandarin dialect was not their primary language.

#### Procedures

After consent was granted, the respondents completed the 69-item CQ-HRQL-CP. In addition, 20 out of 45 respondents were asked to complete the CQ-HRQL-CP twice at an interval of 2 weeks to examine the test-retest reliability.

#### Statistical analysis

Descriptive statistics were applied for basic data on the children and children's families, which was provided by the caregivers (Tables 1 and 2). The item-specific missing rates (number of times an item was not answered) and the ceiling and floor effects

for the CQ-HRQL-CP were calculated. The floor effect was calculated as the percentage of the sample which had the lowest possible score of zero for each dimension; the ceiling effect was calculated as the percentage of the sample the highest possible score of 100 for each dimension.

Item discriminant validity (the degree to which different constructs are correlated) was also evaluated using Spearman's rank correlations ( $\rho$ ). Item discriminant validity evaluates the association of an individual item with its own dimension, compared with its association with other dimensions. An item should correlate more strongly with its own dimension than with any other dimension.<sup>(19)</sup>

The internal consistency of each item was estimated using Cronbach's coefficient,  $\alpha$ , and item-to-total correlation.<sup>(20-22)</sup> An acceptable  $\alpha$  value has been identified as > 0.70.<sup>(20)</sup> We expected excellent overall agreement ( $\alpha > 0.90$ ). For the item-to-total correlation, a value of 0.50 has been recommended as the standard for supporting internal consistency.<sup>(23)</sup>

The intraclass correlation coefficient ( $ICC_{(3,1)}$ ) was used to evaluate the test-retest reliability of the CQ-HRQL-CP. Values < 0.40, 0.40~0.75, and > 0.75 were considered evidence of poor, fair, and good reliability, respectively.<sup>(20)</sup>

## RESULTS

### Sample characteristics

The mean age of the children of the 45 respondents was 8.3 ( $\pm 3.1$ ) years. In 40 (89%) cases, the primary caregiver of the child was the mother. The respondents were primarily mothers (78%) with either senior high or vocational schooling (53%) (Table 2). The mean time taken to complete the CQ-HRQL-CP was 26.8 ( $\pm 9.1$ ) min.

To test the test-retest reliability, the 45 respondents were stratified into 10 groups according to their children's ages, and 2 respondents were randomly selected from each group. The mean age of the children of the 20 respondents selected was 9.3 ( $\pm 3.1$ ) years. In 18 (90%) cases, the primary caregiver of the child was the mother. The respondents were primarily mothers (75%) with either senior high school or vocational schooling (60%) (Table 2). The mean time taken to complete the CQ-HRQL-CP retest was 27.6 ( $\pm 10.9$ ) min.

**Table 1.** Basic Information on Children of Participants in the 2 Study Samples

	Item discriminant validity study sample (n = 45)		Test-retest reliability study sample (n = 20)	
	N	%	N	%
<b>Diagnosis</b>				
Spastic	38	84	18	90
Other	7	16	2	10
<b>Gross Motor Function Classification System</b>				
I	9	20	3	15
II	11	24	6	30
III	9	20	5	25
IV	8	18	3	15
V	8	18	3	15
<b>Gender</b>				
Boy	25	56	13	65
Girl	20	44	7	35
<b>Previous medical intervention</b>				
None	15	33	7	35
Botulinum toxin injections	21	47	11	55
Muscle lengthening	15	33	6	30
Selective dorsal rhizotomy	2	4	2	10
Feeding tube	2	4	1	5
<b>Other chronic diseases</b>				
None	28	62	13	65
Seizures	14	31	5	25
Asthma	2	4	1	5
Cardiac disorder	2	4	0	0
Other	1	2	1	5
<b>Current medications</b>				
None	33	73	16	80
Seizure medication	11	24	3	15
Muscle relaxant	4	9	2	10
<b>Primary locomotion at home</b>				
Child can walk independently without assistance	17	38	9	45
Caregiver assists the child in a cart (or wheelchair) or carries him/her	9	20	2	10
Child can walk with caregiver's assistance	5	11	2	10
Child can crawl	4	9	3	15
Child can walk independently using a walker	4	9	3	15
Child can walk by holding on to furniture	3	7	0	0
Child can roll	2	4	0	0
Child can walk using a walker and with caregiver's assistance	1	2	1	5
Child use a wheelchair indepently	0	0	0	0
<b>Primary outdoor locomotion</b>				
Caregiver assists the child in a cart (or wheelchair) or carries him/her	17	38	7	35
Child can walk independently without assistance	16	36	9	45
Child can walk independently using a walker	7	16	3	15
Child can walk with caregiver's assistance	3	7	0	0
Child use a wheelchair indepently	1	2	0	0
Other	1	2	1	5

**Table 2.** Background Information on Families of Participants in the 2 Study Samples

	Item discriminant validity study sample (n = 45)		Test-retest reliability study sample (n = 20)	
	N	%	N	%
Respondent's relation with child				
Biological mother	35	78	15	75
Biological father	5	11	3	15
Grandfather/grandmother	4	9	1	5
Other	1	2	1	5
Educational level of father*				
Elementary school	2	5	1	5
Junior high school	7	16	2	10
Senior high school/vocational school	20	46	12	60
Technical college	9	21	0	0
University or graduate school	6	14	5	25
Other	0	0	0	0
Educational level of mother				
Elementary school	3	7	1	5
Junior high school	7	16	4	20
Senior high school/vocational school	24	53	12	60
Technical college	4	9	2	10
University or graduate school	7	16	1	5
Other	0	0	0	0
Family members				
Father	43	96	20	100
Mother	42	93	20	100
Grandmother	20	44	8	40
Older brother	14	31	6	30
Older sister	13	29	5	25
Younger sister	12	27	5	25
Younger brother	11	24	6	30
Grandfather	9	20	3	15
Other	14	31	7	35
Other family members requiring additional care				
None	37	82	16	80
Young infant or toddler	3	7	1	5
Other brother/sister with a developmental delay	2	4	2	10
Aging relative with difficulty walking	1	2	0	0
Other	2	4	1	5
Monthly income of the family				
More than 90,000 dollars	8	18	1	5
Between 70,001 and 90,000 dollars	2	4	1	5
Between 50,001 and 70,000 dollars	9	20	5	25
Between 30,001 and 50,000 dollars	11	24	5	25
Less than 30,000 dollars	3	7	2	10
Refused to respond	12	27	6	30

\*: The sample size for the Discriminant Validity and Internal Consistency for this factor was 44, because the parents of one child were divorced, and there was no response to this question.

**Item discriminant validity**

The correlation coefficients for the item-scale correlation with the other dimensions ranged from approximately -0.22 to 0.93 for all 4 dimensions (Tables 3 and 4). Two of the 69 (2.9%) items (one each in the “participation and interaction” and “satisfaction and expectation” dimensions) correlated more strongly with other dimensions than with their

own dimension in the CQ-HRQL-CP and were deleted. For the item-to-total correlation, a value of 0.50 has been recommended the standard for supporting internal consistency. Therefore, another three items with values lower than 0.50 were deleted. In addition, significant ceiling effects were observed for the “pain and emotion” dimension in the 64-item CQ-HRQL-CP (57.8%; Table 4).

**Table 3.** Item-level Analysis and Cronbach’s Coefficients ( $\alpha$ ) for Item Deletion of Individual Questions in the CQ-HRQL-CP

Questions	Motor ability	Pain and emotion	Participation and interaction	Satisfaction and expectation	Item-to-total correlation	Cronbach’s coefficient ( $\alpha$ ) for item deletion
<b>A. Motor ability</b>						
1. Rolls in bed	0.45	-0.19	0.05	0.13	0.45	0.99
2. Creeps forward up to a distance of 2 m	0.63	-0.22	0.23	0.22	0.63	0.99
3. Walks upright at home up to 10 m	0.88	0.12	0.39	0.30	0.88	0.98
4. Walks in community up to 50 m	0.90	0.12	0.46	0.34	0.90	0.98
5. Walks upstairs up to 1 floor	0.90	0.11	0.50	0.38	0.90	0.98
6. Walks downstairs up to 1 floor	0.89	0.10	0.47	0.35	0.89	0.98
7. Steps over obstacles	0.77	0.12	0.42	0.35	0.77	0.99
8. Sits on a high bench for 1 min	0.73	-0.11	0.24	0.22	0.73	0.99
9. Stands alone for 1 min	0.90	0.11	0.43	0.33	0.90	0.98
10. Transfers self to and from a stroller/wheelchair/chair	0.93	0.14	0.43	0.36	0.93	0.98
11. Transfers self from floor to chair	0.89	0.07	0.32	0.26	0.89	0.98
12. Stands up from the floor	0.91	0.06	0.38	0.30	0.91	0.98
13. Gets in and out of a car	0.90	0.07	0.48	0.40	0.90	0.98
14. Grasps and eats a cookie	0.58	-0.13	0.43	0.40	0.58	0.99
15. Holds a spoon and eats by himself	0.72	-0.10	0.36	0.33	0.72	0.99
16. Takes off socks	0.86	0.14	0.52	0.47	0.86	0.98
17. Puts on socks	0.90	0.15	0.47	0.37	0.90	0.98
18. Takes off underwear	0.90	0.19	0.55	0.48	0.90	0.98
19. Puts on underwear	0.91	0.20	0.54	0.47	0.91	0.98
20. Takes off jacket	0.88	0.17	0.49	0.47	0.88	0.98
21. Puts on jacket	0.89	0.17	0.54	0.50	0.89	0.98
22. Takes off pants	0.91	0.24	0.48	0.48	0.91	0.98
23. Puts on pants	0.93	0.18	0.54	0.51	0.93	0.98
24. Goes independently to the toilet	0.87	0.08	0.50	0.36	0.87	0.98
25. Takes a shower	0.78	0.07	0.53	0.40	0.78	0.99
26. Puts on splints (ankle-foot-orthoses) and shoes	0.88	0.13	0.48	0.38	0.88	0.98
<b>B. Pain and emotion</b>						
27. How often does your child experience pain?	-0.08	0.71	0.09	0.09	0.71	0.85
28. How often does your child take a painkiller to control pain?	0.06	0.80	0.22	0.13	0.80	0.84
29. How often does your child experience sleeplessness due to pain?	-0.09	0.89	0.12	0.19	0.89	0.82
30. How often does your child/you change posture or gait due to pain?	-0.14	0.76	0.09	0.02	0.76	0.84
31. How often does pain interfere with your child’s self-care ability?	0.03	0.83	0.06	0.12	0.83	0.83
32. How often does your child throw tantrums?	0.27	0.34	0.05	0.27	0.34	0.90
33. How often does your child get upset with himself/herself?	0.08	0.41	0.22	0.33	0.41	0.89

**Table 3.** Item-level Analysis and Cronbach's coefficients ( $\alpha$ ) for Item Deletion of Individual Questions in the CQ-HRQL-CP (Continued)

Questions	Motor ability	Pain and emotion	Participation and interaction	Satisfaction and expectation	Item-to-total correlation	Cronbach's coefficient ( $\alpha$ ) for item deletion
<b>C. Participation and interaction</b>						
34. Child interacts with primary caregiver	0.01	-0.13	0.57	0.34	0.57	0.86
35. Child interacts with family (including siblings)	0.14	-0.00	0.67	0.45	0.67	0.84
36. Child interacts with relatives (neighbors)	0.17	0.07	0.63	0.55	0.63	0.85
37. Child interacts with peers who do not have developmental delays	0.26	0.13	0.50	0.47	0.50	0.86
38. Child participates in family activities	0.41	0.15	0.55	0.53	0.55	0.85
39. Child participates in community activities (e.g., parks, community centers)	0.52	0.04	0.49	0.40	0.49	0.87
40. In the classroom*	0.29	0.18	0.64	0.52	0.64	0.85
41. During gym classes*	0.33	0.18	0.72	0.66	0.72	0.84
42. During breaks between classes*	0.20	0.21	0.72	0.55	0.72	0.84
<b>D. Satisfaction and expectation</b>						
Degree of satisfaction with your child's life						
43. Interaction between your child and teachers*	0.00	0.09	0.38	0.53	0.53	0.95
44. Interaction between your child and classmates*	0.18	0.13	0.55	0.57	0.57	0.95
45. Educational services for your child*	0.22	0.18	0.52	0.61	0.61	0.95
46. Medical services for your child	0.14	-0.05	0.55	0.62	0.62	0.95
47. Rehabilitation services for your child	0.11	-0.06	0.40	0.52	0.52	0.95
48. Self-care ability of your child	0.67	0.07	0.52	0.36	0.36	0.96
49. Interaction between your child and family	0.19	0.05	0.60	0.69	0.69	0.95
50. *Participation of child	0.33	0.13	0.65	0.68	0.68	0.95
51. Child's participation to family activities	0.27	0.17	0.44	0.61	0.61	0.95
52. Child's sleep quality	0.36	0.25	0.57	0.63	0.63	0.95
53. Child's happiness	0.17	0.27	0.59	0.72	0.72	0.95
54. Child's overall improvement	0.31	0.17	0.59	0.70	0.70	0.95
55. Child's health-related quality of life	0.38	0.26	0.55	0.64	0.64	0.95
Your expectations for your child for the next year						
56. Health	0.36	0.15	0.45	0.67	0.67	0.95
57. Growth	0.35	0.15	0.47	0.56	0.56	0.95
58. Development	0.46	0.13	0.59	0.75	0.75	0.95
59. Learning	0.40	0.15	0.60	0.73	0.73	0.95
60. Life	0.44	0.25	0.64	0.67	0.67	0.95
Degree of satisfaction with caregiver's personal life						
61. Interaction between you and your child	0.20	0.20	0.53	0.73	0.73	0.95
62. Your ability to take care of your child with CP	0.25	0.12	0.58	0.67	0.67	0.95
63. Interaction between you and your family	0.11	0.13	0.45	0.71	0.71	0.95
64. Your ability to take care of your family	0.22	0.18	0.33	0.62	0.62	0.95
65. Your health condition	0.27	0.18	0.39	0.64	0.64	0.95
66. Your sleep quality	0.28	0.22	0.48	0.69	0.69	0.95
67. Your relief from pressure	0.24	0.37	0.38	0.69	0.69	0.95
68. Your happiness	0.17	0.21	0.42	0.70	0.70	0.95
69. Your overall health-related quality of life	0.27	0.32	0.45	0.72	0.72	0.95

\*: Five caregivers could not respond to these items because their children were not attending school at the time of data collection. It has been suggested that the items highlighted in gray be deleted in the 64-item CQ-HRQL-CP.



**Table 4.** Item-to-total Correlation and Cronbach's Coefficients ( $\alpha$ ) for the 4 Dimensions: Statistical Summary of CQ-HRQL-CP Psychometric Testing (45 caregivers)

CQ-HRQL-CP	Dimension	Items	Mode	Median	Range	Mean	SD	(% floor effect)	(% ceiling effect)	†	Cronbach's coefficient ( $\alpha$ )	Item-to-total correlation range	Item-to-total correlation (<0.50) <sup>‡</sup>
A.	69-item	『Motor ability』	26	17.3*	51.9	0~100	52.1	31.7	2.2	2.2	0 (0%)	0.45~0.93	1 (3.9%)
	64-item		25	0*	51.0	0~100	50.9	32.5	4.4	2.2	0 (0%)	0.61~0.94	0 (0%)
B.	69-item	『Pain and emotion』	7	96.4	89.3	17.9~100	85.6	17.1	0	15.6	0 (0%)	0.34~0.89	2 (28.6%)
	64-item		5	100	100	10.0~100	89.8	19.5	0	57.8	0 (0%)	0.64~0.94	0 (0%)
C.	69-item	『Participation and interaction』	9	88.9	77.8	30.6~100	76.7	16.5	0	6.7	1 (11.1%)	0.49~0.72	1 (11.1%)
	64-item		8	75.0	80.0	28.1~100	79.0	16.1	0	8.9	0 (0%)	0.53~0.84	0 (0%)
D.	69-item	『Satisfaction and expectation』	27	69.4	63.9	36.5~100	64.9	14.8	0	2.2	1 (3.7%)	0.32~0.75	1 (3.7%)
	64-item		26	71.2	66.4	40.0~100	65.8	14.9	0	2.2	0 (0%)	0.55~0.77	0 (0%)

\*: There are multiple modes. The smallest value is shown; †: Item discriminant validity: the number of the items in which the item-scale correlations with other dimensions was higher than the item-to-total correlations with their own dimensions; ‡: The number of items in which the item-to-total correlations were lower than 0.5. The first responses of the 45 caregivers were considered for the calculations.

**Internal consistency**

The results of the item-to-dimension and item-to-total correlations are presented in Table 3. Cronbach's coefficient values were calculated as a measure of the internal consistency of the 69-item CQ-HRQL-CP and found to range from 0.86 (“interaction and participation” dimension) to 0.99 (“motor ability” dimension; Table 4). During the item-to-total correlation analysis for the selection of items, 5 items were deleted because their item-to-total correlation values were < 0.50 (2 of these 5 items had already been deleted during item discriminant validity testing). The adjusted Cronbach's coefficient values ranged from 0.87 (“interaction and participation” dimension) to 0.99 (“motor ability” dimension).

**Test-retest reliability**

The ICC<sub>(3,1)</sub> for the 4 dimensions ranged from

0.86 (“interaction and participation” dimension) to 0.99 (“motor ability” dimension). The test-retest reliability was excellent (Table 5).

**Table 5.** Test-retest Reliability of the 4 Dimensions and the Total Test of the 64-item CQ-HRQL-CP

	Dimension (number of items)	ICC <sub>(3,1)</sub>
A.	Motor ability (25)	0.99
B.	Pain and emotion (5)	0.89
C.	Participation and interaction (8)	0.86
D.	Satisfaction and expectation (26)	0.95

## DISCUSSION

The CQ-HRQL-CP was developed as a disease-specific HRQL instrument for children with CP in Taiwan. Although the pre-tested CQ-HRQL-CP consisted of 69 items, we deleted 5 items based on psychometric testing because they correlated weakly with their own designated dimensions. The remaining 64-item CQ-HRQL-CP demonstrated excellent internal consistency (Cronbach's coefficient [ $\alpha$ ], 0.87~0.99; test-retest reliability [ICC<sub>(3,1)</sub>], 0.86~0.99). The mean time taken to complete the CQ-HRQL-CP was 26.8 ( $\pm$  9.1) min. Consequently, the CQ-HRQL-CP could be considered a quick and reliable instrument to measure HRQL in children with CP from the caregiver's perspective.

There were significant ceiling effects for some items of the CQ-HRQL-CP, specifically the items in the "pain and emotion" dimension. According to a previous study, pain is an important issue in children with CP.<sup>(24,25)</sup> In the present study, 26 (58%) respondents indicated that their children did not suffer from pain, which was an unexpected result. To ensure that the cases sampled for testing the test-retest reliability were stable, respondents who were caregivers of children who had surgical intervention or an accident were excluded from the present study. It is possible that the significant ceiling effect in the "pain and emotion" dimension in this study was due to the sampling technique. The respondents in this study were selected using nonprobabilistic sampling, more specifically, convenience sampling. Furthermore, they were recruited from hospital settings. Most of their children received physical therapy regularly. Since the provision of physical therapy for children with developmental delays, inclusive of CP, is not mandated by law in Taiwan, these children probably represent a well-cared-for population because their families are willing to provide routine access to physical therapy. To be eligible for inclusion in this study, all respondents were also literate and capable of reading Mandarin. It is possible that these respondents had a better understanding of the instructions given in home programs and were good at mastering handling techniques appropriately at home. Consequently, the children suffered little or no pain. Future studies are necessary to assess the performance of the CQ-HRQL-CP using a population-

based approach with participants who have other conditions, such as postoperative orthopedic patients. Additional studies should expand the inclusion criteria and employ random selection of participants either from different healthcare systems or across the spectrum of gross motor function to verify the ceiling effects.

Several psychometric properties still need to be examined before the CQ-HRQL-CP can be used in clinical practice. First, factor analysis testing was not preformed because of the small sample size in this preliminary study. The items were grouped based on a literature review and the opinions of the content experts. Therefore, it is necessary to recruit a larger sample and conduct factor analysis to confirm the 4 dimensions of the CQ-HRQL-CP, namely, motor ability, pain and emotion, interaction and participation, and satisfaction and expectation. With factor analysis, the items can be verified into factors to identify distinct constructions. Second, subsequent testing of the concurrent validity of the CQ-HRQL-CP is an important step to assess whether the CQ-HRQL-CP can be used in place of other valid and reliable HRQL instruments, such as the CHQ or the PedsQL in Taiwan.<sup>(11,26-28)</sup> Third, further study may be required to test the responsiveness of the CQ-HRQL-CP to detect score changes among children undergoing medical management. The CQ-HRQL-CP originally devised for children who have had orthopedic surgery offers clinicians and researchers an additional tool which functions as a comprehensive assessment of HRQL in children with CP. Lacking mutual responsiveness and comparisons with other validated instruments, our clinicians and researchers were unable to determine whether changes in CQ-HRQL-CP scores reflected genuine improvements and whether the questionnaire was more relevant to the CP population in Taiwan. Eventually, inter-tester reliability is also necessary. The CQ-HRQL-CP in the present study was used to assess HRQL in children with CP through their caregivers' responses. Previous studies have indicated that the perceptions of HRQL or quality of life in children with CP may differ between children and their caregivers.<sup>(28,29)</sup> In other words, since there may not be unanimous consensus between parental caregivers and their children, the findings of the present study should be used with caution. Needless to say, it is important to fully explore each single perspective.

In this preliminary study, the primary caregivers of the 4- to 14-year-old children with CP were asked to respond to the CQ-HRQL-CP. To our surprise, 5 of the 45 children had not received any schooling. According to the Special Education Law (SEL) in Taiwan, public educational institutions have an obligation to educate children 3 years old and older with developmental delays. This current study purposely maintained the integrity of SEL by applying relevant items to the CQ-HRQL-CP in the hope that questions will subsequently emerge which elevate the educational status of children with CP, which is a crucial part of their HRQL.

In conclusion, this preliminary study analyzed the psychometric properties of the CQ-HRQL-CP. There were some limitations, such as the small sample size and the case selection, across tests. Future study should include validation of this version of measures, employment of larger sample sizes, and follow up studies of the ceiling effects in assessing the "pain and emotion" dimension in groups with specific conditions, such as children with orthopedic problems. Testing of the concurrent validity, responsiveness comparisons with other foreign HRQL instruments, and publication of minimal clinically important differences are needed for continued development of the CQ-HRQL-CP.

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# 腦性麻痺兒童的健康相關生活品質照顧者問卷的建構與信、效度測試之前驅研究

劉文瑜 侯玉真<sup>1</sup> 廖華芳<sup>3</sup> 林燕慧 陳玉瑩<sup>4</sup> 黃美涓<sup>2</sup>

**背景：**台灣尚沒有量測腦性麻痺兒童的健康相關生活品質的疾病特定性 (disease-specific) 工具。本前驅研究的目的是要發展出腦性麻痺兒童的健康相關生活品質照顧者問卷 (Caregiver Questionnaire of Health-Related Quality of Life in Children with Cerebral Palsy, CQ-HRQL-CP)，並檢測這份問卷的信、效度。

**方法：**CQ-HRQL-CP 包括動作能力 (motor ability)、疼痛與情緒 (pain and emotion)、互動與參與 (interaction and participation) 和滿意程度及期許 (satisfaction and expectation) 等 4 面向。以內容效度指數 (Content Validity Index, CVI) 來進行問卷的修改。項目區辨效度 (item discriminant validity) 和內部一致性 (internal consistency) 信度的測試是採取立意取樣 (purposive sample) 的方式徵召 45 位腦性麻痺兒童家長參與。以 45 位中，再隨機選擇 20 位家長進行再測信度 (test-retest reliability) 測試。

**結果：**問卷之 CVI 值範圍介於 0.86 至 1。至於項目區辨效度則以一個題目與其他面向的相關性若大於與本身面向的相關時，這個題目就必須被刪除。調整後的 Cronbach's alpha 係數在各面向範圍為 0.87 至 0.99。再測信度是使用類組間相關係數 (Intra-class correlations) 計算，各面向範圍為 0.86 至 0.99。

**結論：**新發展出來的 CQ-HRQL-CP 具可接受的內容效度、項目區辨效度、內部一致性與再測信度。未來研究將檢測 CQ-HRQL-CP 的同時效度 (Concurrent validity)。  
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**關鍵詞：**腦性麻痺，健康相關生活品質，效度，信度

長庚大學 醫學院 物理治療學系；<sup>1</sup>長庚醫療財團法人嘉義長庚紀念醫院；長庚大學 醫學院；<sup>2</sup>長庚醫療財團法人桃園長庚紀念醫院 復健科；長庚大學 醫學院；<sup>3</sup>長庚醫療財團法人林口長庚紀念醫院 兒童骨科；<sup>4</sup>台灣大學 醫學院 物理治療學系暨研究所

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通訊作者：黃美涓醫師，長庚醫療財團法人桃園長庚紀念醫院 復健科。桃園縣333龜山鄉舊路村頂湖路123號。

Tel.: (03)3281200轉2655; Fax: (03)3198222; E-mail: walice@cgmh.org.tw